NATIONAL STEERING GROUP FOR SPECIALIST CHILDREN'S SERVICES IN SCOTLAND
MINUTES OF MEETING – FRIDAY 9 NOVEMBER 2007
CONFERENCE ROOM 3, VICTORIA QUAY, LEITH, EDINBURGH

Present:
Malcolm Wright, Chair, Chief Executive, NHS Education Scotland
Dr Michael Bisset, Clinical Director, Royal Aberdeen Sick Children's Hospital
Helen Byrne, Director of Acute Services Strategy Implementation and Planning, NHS Greater Glasgow and Clyde
Professor Sir Alan Craft, Past-President of the Royal College of Paediatrics and Child Health
Fiona Drimmie, Associate Postgraduate Dean, NHS Education for Scotland
Dr Zoë Dunhill, Patients' Services Director and Community Paediatrician, Royal Hospital for Sick Children, Edinburgh
Deirdre Evans, Director, National Services Division
Joanne Gillies, Workforce Unit, Scottish Executive Health Department
Heather Knox, West Regional Planning Manager, West of Scotland Regional Planning Group
Annie Ingram, North of Scotland Regional Planning Group
Morgan Jamieson, National Clinical Lead for Children and Young People's Health in Scotland
Anne Leigh-Brown, Programme Principal, Women & Children's Health Information Programme, Information Services Division
Isabel McCallum, Clinical/Project Director – Reprovision of Royal Hospital for Sick Children, Edinburgh
Jackie Sansbury, Director of Strategic Planning, NHS Lothian
Iain Wallace, Associate Medical Director, NHS Greater Glasgow and Clyde, Women's and Children's Directorate
Anne Wilson, Action for Sick Children Scotland

In Attendance
Andrea Cail, Senior Project Manager, Children and Young People's Specialist Services Team
John Froggatt, Deputy Director, Child and Maternal Health Division, Scottish Government
Violet Jardine, Consultant
Dr Margaret McGuire, Nursing Officer, Scottish Executive Health and Wellbeing
Ken Mitchell, Senior Project Manager, Children and Young People's Specialist Services Team
Mary Sloan, Child and Maternal Health Division, Scottish Government
Louise Smith, Senior Medical Officer, Scottish Government
Robert Stevenson, Head of Children and Young People's Specialist Services Team, Scottish Government
Russell Whyte, DTZ

Apologies
Sharon Adamson, West of Scotland Regional Planning Group
Colin Cook, Deputy Director, Healthcare Planning and Support, Scottish Government
Lorraine Currie, Chair Child Health Commissioners' Group
Myra Duncan, Regional Planning Director, South East and Tayside Regional Planning Group
Ellen Finlayson, CLIC Sargent
Rory Farrelly, Nursing Officer, Women and Children, Scottish Executive Health and

Wellbeing Directorate
Professor Stewart Forsyth, Medical Director, NHS Tayside
Jamie Houston, Consultant, Oban and Lorne Hospital
Adrian Margerison, Scottish Officer, Royal College of Paediatrics and Child Health
Professor George Youngson, Consultant Paediatric Surgeon, NHS Grampian

ITEM 1 WELCOME AND APOLOGIES

1. Malcolm welcomed everyone to the quarterly meeting of the National Steering Group for Specialist Children's Services in Scotland. He particularly welcomed Anne Wilson to her first meeting, representing Action for Sick Children (Scotland) in place of Rebecca Strachan, and Joanne Gillies who is now Head of the Scottish Government's Workforce Unit. Malcolm also welcomed Violet Jardine who has been engaged to produce the National Delivery Plan and informed the meeting that Russell Whyte from DTZ would be joining them later to give an update on the cost analysis exercise which was currently underway.

2. Malcolm went on to say he hoped the meeting would consider the draft reports, which had been circulated at a high level; it would not be possible to debate all the issues. He wanted to refine the recommendations; agree priorities and identify who should be responsible for each action, to feed into the National Delivery Plan. He reminded the meeting of the tight timetable: an event was taking place on 26 November; the next Steering Group meeting, to discuss the draft National Delivery Plan, would take place on 7 December; the Plan would be discussed by the Children and Young People's Health Support Group at its meeting on 17 December; after which it would be submitted to the Cabinet Secretary for Health and Wellbeing at the end of December.

3. Malcolm went on to say the National Delivery Plan would have to dovetail with other work which was underway, ie the neurosurgery review, the *Better Health Better Care* consultation and Derek Feeley's planning and commissioning work.

4. Malcolm suggested the meeting should bear in mind the following issues:

- The outcomes should facilitate equity of access
- Workforce - in particular the impact of impending retirals
- The fixed points – the 4 children's centres (Aberdeen, Dundee, Glasgow and Edinburgh) and the sustainability of the 2 paediatric intensive care units
- The regional and national networks.

5. Malcolm concluded by saying the National Delivery Plan presented the best opportunity in a decade to produce a blueprint for action – the Group had to refine the reports into cohesive recommendations bearing in mind the main aim was to improve outcomes for children and young people in Scotland.

ITEM 2 NATIONAL DELIVERY PLAN FOR SPECIALIST CHILDREN'S SERVICES IN SCOTLAND

2.1 CHALLENGES

6. Morgan Jamieson began by suggesting the Group were well versed in the issues which had prompted the specialist children's services review which included:

Concerns:

- The differences in outcomes for children around the country: the need to improve clinical and care outcomes for children and young people
- The small numbers involved in many specialties
- Scotland not matching survival rates in other European countries eg cancer, cystic fibrosis: the need to be as good as we can be within the UK and beyond
- Sustainability – some services were vulnerable due to impending retirals and sick leave – not just at consultant level
- Workforce issues – roles, upskilling/training
- Inequity and inconsistency of service provision
- Access issues and "inappropriate" care, eg for young people.

Contraints:

- Historic service models which have mainly developed around the medical schools
- NHS structures – 14 NHS Boards, NSD, NES etc
- Geography/demography – the 2 main cities are close together
- Differences in public opinion and professional opinion – strong feelings about local services
- Resources

Frustrations:

- The recommendations in previous reports not being actioned eg neurosurgery, gastroenterology, cancer
- A piecemeal approach – looking at individual services in isolation, not looking at interaction or critical mass
- Planning and commissioning.

7. Morgan summed up by suggesting these cross-cutting issues needed cohesive answers.

8. During discussion, it was pointed out:

- A "big picture" overview was needed at the beginning of the report
- The outcome of the Comprehensive Spending Review will have an impact
- Boards have responsibility for ongoing services
- Workforce must be considered as a whole – staff should be flexible and willing/able to work across different sectors
- Agenda for Change has had a serious impact on recruitment/retention. There are differences in grading within and outwith Scotland– eg senior AHPs have been graded higher in England than in Scotland

2.2 PRINCIPLES AND VALUES

9. Robert Stevenson reported that the first draft of the reports would be pulled together to form the draft National Delivery Plan which would be discussed at the next National Steering Group meeting on 7 December.
Action: members to submit comments on the reports by email or by telephone to Robert Stevenson.

10. During discussion, the following points were raised:
- The National Delivery Plan had to address outcomes, sustainability, research and development
- It should concentrate on service delivery and reinforce Networks of Care
- Service delivery should be planned considering the child as a whole, ie including local authorities and voluntary organisations as well as NHS Scotland
- Child protection issues should be included
- Links with District General Hospitals (DGHs) must be incorporated
- The health focus in the National Delivery Plan must be strong and be holistic.

2.3 PLANNING AND COMMISSIONING

11. Malcolm Wright reported he had discussed planning and commissioning with Derek Feeley who wanted a holistic approach. The Steering Group should feed in to the *Better Health Better Care* document. This Group could suggest what services should be planned nationally, regionally and locally. Robert went on to point out that the paper was a very first draft of clear statements of where services should be delivered and acknowledged the comments Deirdre Evans had submitted. The Group had to decide the main issues to address which should feed into the National Delivery Plan and into Derek Feeley's work.

12. During discussion, the following points were raised:
- The paediatric cardiac surgery service had not been developed as a result of the Bristol inquiry – it was in place before the inquiry reported
- The recommendation on the arrangements for prioritisation of services and the criteria to use (page 5 of the report) should be clearer – services should be set up before crises happened
- The list of nationally designated services should be expanded (page 5 of the report)
- Links must be maintained between specialist and non-specialist services - integrated local service provision/commissioning should be linked with specialist commissioning
- Pathways of care needed to be emphasised – the English NSF contained good pathways. The Child and Maternal Health Information Strategy Group were also looking at pathways of care
- Immunology was not included
- Regional planning should be tightened up
- The paper would be amended in light of comments received
- Directors of Planning Groups are working on planning hierarchies – concerns were raised about duplication of work.

Action: Heather Knox to assist in tightening up and clarifying the regional planning issues.

2.4 WORKFORCE

13. Annie Ingram began her presentation by thanking Jim Beattie and Sandra Hay for their hard work. She went on to point out the key issues in the report. She acknowledged the information was not sufficiently refined – there was little sub-specialty information available and the nursing and AHP information was inaccurate.

14. The Royal College had conducted the medical census by sending questionnaires to the Clinical Directors of Child Health – there had been an 80% response rate but the returns were not all accurate. In January 2007, there were 384 doctors employed in paediatrics in Scotland: of these 220 were consultants. 57 of these consultants spent 100% of their time in sub-specialty paediatrics. 63% of the workforce was female.

15. DGHs were reliant on non-consultant grades – if staff left the service would be under threat. Within the next 10 years, up to 50% of staff might have to be replaced. 63 doctors in consultant jobs were over the age of 55 – probably 70 doctors would be needed to replace these 63. Expertise is needed to deal with specialties – training was an issue.

16. Annie raised her concern that all the reports included recommendations on workforce and these should be included in the workforce report. She also questioned whether the level of suggested increased staffing was affordable or achievable – was the staff available to recruit? Annie went on to point out the recommendations contained in the workforce report:

- Data – NHS Scotland should be clearer on what data it wanted to collect to improve the quality of data available. Workforce projections needed a consistent approach based on population need. Emerging models of care would require different roles. Risks should be identified, eg retirals

- Nationally – fit for purpose training programmes were needed. Specialist skills were needed to treat very sick children – specialist AHP roles should be considered. Where a national network was proposed Boards must be obliged to replace staff according to the network plan

- Regionally – Child Health Groups must work together to look at the demography of the workforce and develop plans to address. The Groups should review risks and develop new workforce models. Managing Medical Careers had put some services at risk

- Board – Boards were not Working Time Regulations compliant. They should review long term locums and seek to replace with permanent doctors in very specialist services.

17. During discussion, the following points were raised:
- It was difficult to obtain data on the multi-professional workforce
- Decisions had to be taken on how to prioritise the recommendations from the various reports
- The recommendations needed to be challenged – should generic capacity be increased?
- Only medical paediatric consultants were included, the surgical and CAMHS workforces were missing

- Some of the training issues were UK-wide issues, eg surgical training
- It was difficult to produce a fit for purpose workforce plan, training was the key – higher education institutions must deliver what was required by the clinical services and must work differently to ensure clinical credibility in delivering competency based programmes
- Aligning training to service need was very important
- The medical models in the reports presented challenges around affordability and availability of staff
- The nursing/midwifery project was looking at acute paediatrics and community/specialist nursing
- The skill mix needed for each model of care for each specialist service had to be considered. This would require re-engineering the workforce – junior doctor issues were being considered
- The right practitioner must be in the right place at the right time – triage and safety was paramount – the Emergency Care Framework for competencies could be taken into account – the Department of Health had done some work on re-engineering
- What patients needed not what consultants want should be borne in mind – consultants had a range of generic skills and specialist skills – both were important. An AHP or consultant with an interest could be appointed and then trained
- Replacements should not always be "like for like"
- Networks were very important – local doctors should link in with their regional and national colleagues and should undertake some work in the main centre
- The MMC initiative was being reviewed
- The NHS must be very clear what data is needed ISD to collect.

18. Malcolm summed up by saying the recommendations would need to be timetabled, ie what should be done in Year 1, Year 2 etc. It was this Group's remit to advise the Scottish Government, to define the services that should be in place and to prioritise the services under most pressure.

2.5 RECOMMENDATIONS

19. This item was taken with Agenda Item 3.

2.6 COST ANALYSIS

20. Russell Whyte from DTZ informed the meeting that the cost analysis had been initiated to get a feel of expenditure in child health services in general and in specialist services in particular. More than £230m was going into child health in Scotland. Russell went on to explain the methodology. He had mapped out the activity in specialist children's services and the cost of delivery. He had used ISD data, which was centrally collected, and provided consistent data sets but he had been unable to match exact specialty definitions. He had looked at inpatient and outpatient hospital services and primary care. The data relied on consistent hospital returns. Some data sets were sample based, eg for GP surgeries. To avoid double counting if a child had 2 or 3 different conditions, Russell had looked at the primary, but not the secondary, diagnosis. This had given him a baseline but he had encountered problems with the available data.

21. For hospital-based cases, Russell had 3 years of data. The findings included:

- Across 12 specialist services, the number of patient episodes was stable, even declining, but costs were increasing
- For inpatient day cases, £51.7m had been spent in 2006 for children up to the age of 18
- General surgery had the highest volume of activity with 48% of episodes but with 28% of the costs
- Cancer amounted to 25% of the total costs, but only 2% of episodes
- The average cost per patient was £2,400 per head, but there was a lot of variance – cancer services incurred 10 times that cost: non malignant haematology, burns and neurosurgery incurred double; dermatology, gastroenterology and general surgery were high volume
- Grampian spent £6m on children: Lothian spent £12.5m. Glasgow, Lothian and Grampian imported inpatients from other areas and had to pay for them. NSD costs had been included
- These costs included infrastructure, ie staff costs, drugs etc
- £16.3m had been spent on outpatients in 2006 – 36,000 attendances
- the highest costs Health Boards were Glasgow - £5.9m and Lothian - £3.9m. Some Boards appeared to be more expensive per patient perhaps because they undertake more specialist services
- For primary services the average cost per attendance was worked out but this was very rough – costs were going up but activity appeared to be going down. There was no breakdown for Health Board areas but £7.8m had been spent in total in Scotland in 2006. Dermatology and respiratory were the highest cost.

22. Russell summarised the points by saying that hospital-based services were the highest costs, amounting to 75% of the total. Cancer and general surgery were the highest cost specialties. Costs were increasing year on year despite the activity remaining stable.

23. During discussion, the following points were raised:

- Caution had to be exercised when looking at trends over just 3 years of data and at looking at only 12, rather than all, specialties
- National Services Division spent £35.5m per year on children's services, mostly on hospital day cases, this expenditure might have been missed – DTZ were invited to visit NSD
- The costs of children being treated outwith Scotland had to be taken into account
- At a high level, these findings seemed right but detailed questions had to be asked
- It was confirmed that "activity" wasn't just the number of heads but included consultant time.

24. Malcolm thanked Russell for his presentation.

Actions:
Data should be quality assured by ISD
A small group, to be established to consider the dradt report
Information on NSD services to be included.

ITEM 3: REPORTS (WORKING DRAFTS)

25. Malcolm suggested that to produce an agreed sensible National Development Plan, the recommendations contained in each report had to be considered.

Age Appropriate Care

26. It was acknowledged that transitions was a gap in the report but Chris Kelnar was leading a group looking at this. The meeting raised the following points:

- The Action Framework recommended that Boards should have action plans in place to admit children up to the age of 16 to children's hospitals: facilities should be in place for 16-18 year-olds
- Some specialties treat children up to age 16 now.

Cancer

- The tight revenue position means the recommendations must be prioritised and phased in over a few years
- The MCN was the key driver in making changes in practice and should feature at the beginning of the report
- A Lead had been appointed by the Network – contracts were an important issue when staff were being appointed to services rather than to Health Boards
- It should be made clear if cancer was to be delivered as an MCN or a Managed Service Network
- Staff must be employed by a legal entity, ie a Health Board. Resources must be established and agreed, the role has to be defined and Boards have to agree to re-appoint when staff leave
- The National Delivery Plan should focus on outcomes and Boards should then decide how to appoint
- Although there had been a good measure of agreement at the meeting on 1 October, issues still had to be resolved, eg although the meeting appeared to agree that there should be one centre, not all groups that day had agreed to that
- a "virtual" Primary Treatment Centre (PTC) would make the service permissive and provide a single service in Scotland delivered in different places
- the recommendations were not clear on what should be done, where but it was suggested they shouldn't be too specific or there wouldn't be a permissive service
- the report could outline the pathways but not stipulate whether there should be one or 2 PTCs because the outcome of the neurosciences review would influence that decision
- one site should lead on clinical trials
- the levels of care must be included in the recommendations.

27. Malcolm summed up by saying that Scotland needs at least one Primary Treatment Centre; the neurosciences decision was awaited and would influence the recommendations in the National Delivery Plan; Glasgow was level 4 now and would remain so, Edinburgh would be level 4 or level 3+ depending on the outcome of the neurosciences review; the Managed Clinical Network (MCN) was in place but needed to be well resourced; thought still had to be given to the European clinical outcomes.

Action: assimilate comments submitted by Jackie Sansbury, share them with Group and refine the recommendations as necessary.
Comments on the reports to be submitted to Robert Stevenson by close of play on Wednesday 14 November.

Dermatology

28. The recommendations included non-specialist issues – specialist issues should be identified.

Endocrinology

29. The report recommended the establishment of a national Managed Service Network. Annie Ingram explained the difference between a Managed Clinical Network (MCN) and a Managed Service Network. An MCN was defined in a health department letter and has defined protocols and linkages. A Managed Service Network was an MCN plus service delivery, eg delivering a service over several Boards, and planning/commissioning. Ownership was a problem with a Managed Service Network. Each report should be clear as to whether it was recommending a Managed Clinical Network or a Managed Service Network.

30. Information gained through engagement with Glasgow and Edinburgh still had to be incorporated into the report. Endocrinology was being delivered as a national service in an ad hoc way providing outreach services.

Emergency Care

31. Performance management should be included in the National Delivery Plan for all specialties. The Boards would be contacted soon regarding implementation of the Emergency Care Framework for Children and Young People in Scotland. Emergency Care would be included in the National Delivery Plan for completeness.

Gastroenterology

32. Gastroenterology should be a priority as the service was under significant pressure. Boards have to sign up to the recommendations or they wouldn't be implemented. The groups which had produced the reports could be challenged at the event on 26 November.

General surgery

33. Looking at the number of children treated by this service, it was suggested this should be a priority. The recommendations should emphasise the need for a designated lead anaesthetist. The recommendations on training and staffing were not specific or firm enough.

Metabolic Disease

34. Significant progress had already been made on implementing the recommendations but the service should be revisited to make further recommendations.

Complex Respiratory/Cystic Fibrosis

35. It was suggested this service should be a priority. The service was near collapse or access to specialsit componenets was non-existent in some NHS Board areas, significant challenges had to be addressed. A 2002 report on cystic fibrosis had not been implemented due to resource implications. Discussions should take place on whether to adopt the very

high Cystic Fibrosis standards – they could be a hindrance if the bar were set too high. The recommendation could say that Boards/Regions would work towards meeting the Cystic Fibrosis Trust Standards rather than saying Boards/Regions were to meet the CF Trust standards. Another set of, achievable, standards should perhaps be drafted. The Group had to bear in mind that its remit was to advise Ministers on the best services for children.

Rheumatology

36. Early diagnosis of rheumatology was a key issue – if children were treated quickly it avoided problems in adulthood.

Telemedicine

37. The Group thought this was a good report but there had been no opportunity to discuss it. Telemedicine could reduce other costs.

General comments

38. District General Hospital consultants functioned with a special interest through goodwill and not through planning. A consultant who was retiring could be replaced with a different type of consultant – jobs could be created in different ways although a certain number of paediatricians would be needed to deliver a service, they couldn't all be replaced by nursing staff. Manpower recommendations were based on best guesses.

39. Thought had to be given on which services to prioritise and also on how to prioritise the recommendations in all the reports to ensure they were implemented. A criteria should be worked out. The recommendations would be considered further at the Open Meeting on 26 November. Concerns were raised about accepting the reports without having the opportunity to challenge them. Concerns were also raised about the need to pull out common themes from all the reports and the time available to do that. Not all services could be a priority. Boards couldn't be instructed to prioritise services which they couldn't afford.

Members to send their comments on the reports to Robert Stevenson by close of play on Wednesday 14 November.

ITEM 4 NATIONAL DELIVERY PLAN NATIONAL SEMINAR – 26 NOVEMBER 2007

40. It was hoped to present a set of recommendations on the 26th to allow for discussion on what should be included in the National Delivery Plan. The morning session would focus on service elements: the afternoon session would be chaired by the BBC Political Editor, Brian Taylor, and would focus on cross-cutting themes. The morning would also feature an Open Forum during which delegates could wander around and choose the subjects of most interest to them.

41. Concerns were raised that the Group members were also Board employees and they would find it difficult to make recommendations that the Boards wouldn't be able to deliver. However the Group had to make recommendations on how to improve services. The Delivery Plan would provide a direction of travel – if the recommendations were not financially possible, this needed to be flagged up to Ministers. Concerns were also raised that

the event would not give sufficient opportunity to challenge the reports. NHS Scotland should seek to achieve the same standards as the rest of Europe and should work in a networked way to achieve them.

42. Workforce issues should be discussed on the day. Redesign and re-engineering of the services may be required, for example a generic nurse could be employed to free up time for experienced AHPs. There was a need to maximise the available workforce.

43. Some of the recommendations in the reports could be taken forward without extra resources. Alternative ways of delivering services should be considered. The outputs should be tested on the day. After 26 November, difficult decisions on priorities would have to be taken. The draft National Delivery Plan would be issued for formal 3 months' consultation – the outputs and recommendations would be tested then.

44. John Froggatt reminded the meeting that the Scottish Government was adopting an outcome-based approach. If outcomes were set out in the recommendations, the detail on how to achieve them might be for the Health Boards to deal with. The National Delivery Plan was a great opportunity to improve specialist children's services. Whatever the outcome of the strategic spending review, there would be an expectation on Health Boards to redesign services to deliver. It was this Group's remit to advise the Cabinet Secretary for Health and Wellbeing on specialist children's services.

Action: Members to comment to Robert Stevenson on the reports and recommendations by 14 November.
The 26 November event would provide an opportunity for the recommendations, and the Lead clinicians, to be challenged: comments made on the day to be taken into account when drafting the National Delivery Plan.
The National Steering Group to meet on 7 December to discuss the draft Plan.

45. Malcolm summed up by saying more work had to be done on the economic review and this should be shared again with the Group. The workforce and resource implications had to be synthesised. The Group had to agree on the issues to be prioritised. The Plan would then be submitted to the Children and Young People's Health Support Group before being submitted to the Cabinet Secretary for Health and Wellbeing.

46. Malcolm closed the meeting by thanking everyone for their worthwhile contributions and reminding them to send comments on the reports to Robert Stevenson by 14 November. The next National Steering Group meeting would take place on Friday 7 December at 2pm in Conference Room 1, Victoria Quay, Leith, Edinburgh.

47. The remaining agenda items were not taken.